Psychosocial care and patient autonomy: a feminist argument in support of a “meaning-making” intervention

Jennifer Bell

Faculty of Graduate Studies, Department of Philosophy
McGill University, Montreal

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Abstract

Recent studies in psychosocial oncology that seek to address the social, psychological, emotional, spiritual, quality of life, and functional impacts of cancer, report positive findings for meaning-making interventions designed to help cancer patients cope with their illness experience. These interventions are successful in decreasing depression among cancer patients and increasing life satisfaction, self-esteem, coping, physical functioning, and optimism. Yet, despite these positive findings meaning-making interventions and, more generally psychosocial care, are not well integrated into hospital or healthcare organization routine cancer patient care.

This thesis explores practical, theoretical, and bioethical barriers to integrating psychosocial care, focusing primarily on the latter considerations. I will argue that meaning-making interventions fall within the bounds of healthcare professionals’ capacities and duty to care, more to the point, as necessary for quality cancer patient care. The bioethical principle of respect for autonomy, when reconsidered from a feminist standpoint, morally requires the intervention’s inclusion in routine care.
Abrégé

Les études récentes dans l'oncologie psychosocial qui cherche à adresser les effets sociaux, psychologiques, émotives, spirituelles, qualité de vie, et sur les impacts fonctionnels du cancer ont démontré des résultats positifs pour les interventions créant une signification conçu pour aider ceux qui ont le cancer à faire face à leur maladie. Parmi les malades, ces interventions réussissent à réduire la dépression, et à augmenter la satisfaction de vie, l'amour-propre, l'abilté de se débrouiller avec la maladie, le fonctionnement physique, et l'optimisme. Pourtant, malgré ces conclusions positives, les interventions faisant la signification et, plus généralement, le soin psychosocial, n'est pas intégré dans l'hôpital ni dans la politique d'organisation des services médicaux pour le soin standard des patients souffrant du cancer.

Cette thèse explore les obstacles pratiques, théoriques, et bioéthiques à l'intégration des soins psychosociaux dans la politique, concentrant principalement sur les considérations dernières. Je disputerai que l’intervention se trouve parmi les capacités et les obligations à soigner des professionnels de services médicaux et, de plus important, sont nécessaires au soin de bonne qualité des patients de cancer. Le principe bioéthique de respect pour l'autonomie, lorsque reconsidéré d'un point de vue de féminisme, exige moralement l'inclusion de l'intervention dans la politique des professionnels de services médicaux.
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Introduction

Psychosocial oncology is a sub-specialty of oncology that seeks to document and address the social, psychological, emotional, spiritual, quality of life, and functional impacts of cancer across the trajectory from prevention to bereavement (Canadian Association of Psychosocial Oncology, 1999). Psychosocial care is, generally, the practice or incorporation of treatment interventions or assistance to address these impacts in cancer patients either individually or in a group setting.¹

Recent work in psychosocial oncology and nursing research, notably within the last decade, has focused on the role of beliefs in cancer patient perceptions of well-being and life satisfaction. Beliefs in this context largely refer to how persons with cancer view the world and determine how they perceive life, think, communicate, feel and behave (Erikson et al., 1983).

Similar to beliefs, the process of finding meaning in illness has also been the focus of nursing theorists as it has been found that patients help create perceptions of their health by establishing meaning in illness situations (Richer, 2000, p. 1109; Parse, 1987). Finding meaning in illness involves an existential and self-reflective process whereby patients situate the illness experience and make sense of it within a larger framework of their belief system and against the backdrop of their life experiences and future expectations (Lee et al., 2004, p.298).

Utilizing the role of patients’ beliefs, a few nursing practitioners specializing in oncology have developed “meaning-making” interventions in order to help individual

¹ This definition was adapted from the Canadian Cancer Society (2006) website; see http://www.cancer.ca/ccs/internet/standard/0,3182,3702_329304_43216412_langId-en,00.html (accessed June 13, 2006).
patients and their families deal with the psychological distress associated with cancer diagnosis or experience. These interventions are adapted from other recent psychosocial interventions or care, which have either adopted a cognitive-behavioural approach to stress reduction (focusing on thoughts, assumptions, beliefs and how they relate to behaviour), provided coping skills training (introducing and supporting a variety of skills and techniques for coping), and/or used a problem-solving skills training approach (introducing and supporting a variety of skills and techniques for problem-solving) (Helgeson, 2005). Meaning-making interventions, designed largely to help cancer patients cope with their illness experience, combine many of the above approaches while paying particular attention to helping patients “reconstruct a world and self view that can assimilate or accommodate the repercussions of cancer” (Lee et al., 2006, p. 292). Most psychosocial interventions, at large, reflect longer standing psychiatric clinical practice where cognitive restructuring therapies, such as psychoanalysis, take the role of challenging seemingly dysfunctional beliefs (those that indicate, for example, a loss of self-value) and enhancing facilitative beliefs (for example, those that contribute to self-worth and self-confidence) (Richer, 2000, p. 1109-1110). These interventions have significance for patient autonomy as autonomous decision-making assumes a patient possesses facilitative belief structures in order for her to be capable of determining what she wants and to give informed consent.

Research studies on meaning-making interventions have indicated exciting,

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2 Ramfelt, Severinsson, and Lutzen, in their study exploring the emotional and interactional perspectives of the meaning of illness in patients with colorectal cancer, identify beliefs related to gratefulness, having confidence in oneself and others, and looking forward to creating a new future as facilitative of emotional recovery. Themes such as altered self-value, loss of temporality, and infringement of body integrity were less facilitative. See Ramfelt, E., Severinsson, E., and Lutzen, K. (2002). Attempting to Find Meaning in Illness to Achieve Emotional Coherence, *Cancer Nursing*, 25,2, pp. 141-149.
positive results. Those cancer patients who received them saw significant decreases in
depression and increases in self-esteem, satisfaction with life, optimism, and feelings of
self-efficacy (Lee et al., 2006; Lee et al., 2004, p. 298; Linn et al., 1982). In a systematic
literature review on meaning and the cancer patient experience, Lee et al. (2004)
identified several other studies that support the value of meaning-making. Degner et al.,
for example, asked 1012 women to describe their experience with breast cancer. The
women who ascribed a positive meaning were reported to have significantly less trait
anxiety, depression, and better emotional functioning and quality of life compared to
women who described a negative meaning (2003). Yet another study (Ramfelt et al.
2002) correlate patients’ self-perceptions and confidence with their views of their cancer
experience; “those patients who viewed their cancer experience as a “challenge” or
“relief” [were identified] as self-confident people who were optimistic about their future,
whereas patients who perceived the cancer as “the enemy” struggled with their self-value
and integrity as a person” (quoted in Lee, 2004, p. 298). Finally, Lee et al. discovered a
plethora of other studies that support these findings; “the ability to find meaning in illness
was consistently associated with positive outcomes, such as higher self-esteem (Lewis,
1989), hope (Post-White, 1996), ability to cope (Barkwell, 1991), better physical

Given the noted success of meaning-making interventions in alleviating cancer
patient psychological discomfort or distress and in promoting emotional well-being it is
disconcerting, at least, that these psychosocial tools are not yet part of routine cancer
patient care. This is not for lack of instructive clinical practice guidelines. Large-scale,
widely accessible, oncology practice and supportive care guidelines, concerned with
articulating the latest in quality cancer patient care have co-opted psychosocial interventions (although not necessarily meaning-making interventions) to a degree. Some years ago funding was made available by the BC Cancer Agency and the BC Cancer Foundation to initiate a province-wide working group to begin the work of developing guidelines for psychosocial care. As a result, the Canadian Association of Pyschosocial Oncology (CAPO) produced national psychosocial standards for oncology patient care. Additionally, Health Canada developed oncology practice guidelines with attention to psychosocial care, which are accessible through one of the largest, if not the most comprehensive, online Canadian clinical guidelines database, maintained by the Canadian Medical Association (CMA). This database, or Infobase, as it is called, is endorsed by national, provincial/territorial and regional health organizations, professional societies, government agencies, and expert panels.

In the Health Canada clinical practice guideline specific to breast cancer psychosocial support is explicitly encouraged in patient follow-up visits with her physician. Indeed, the authors of this document (they are part of a steering committee for the treatment of breast cancer) report psychosocial support as one of four principal objectives of regular follow-up surveillance (Grunfeld, et al., 2006).

Although psychosocial care is included in some oncology clinical practice guidelines as evidenced by CAPO guidelines and the Health Canada document, more needs to be done to ensure its utilization in routine oncology patient care. For example, competing medical and patient priorities may force psychosocial care to take, at times, an improper backseat relative to the decisions that need to be made about physical treatment.

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and symptom management. Furthermore, time and resource constraints may constrict healthcare professionals’ capacities to provide the intervention. In order to implement psychosocial interventions healthcare providers need to be allowed the time to learn the intervention, time to talk to the patients, and the physical space required for the private discussions.4

As demonstrated by the success of the aforementioned psychosocial research findings, the inability for healthcare professionals to routinely provide this care and support should not be taken lightly. Profound positive improvements to cancer patients’ quality of life, ability to cope, and sense of well-being are all in the attainable midst. Considering that cancer may not be curable and that it can profoundly affect a person’s life, where those who experience cancer as a disease that plays itself out as chronic illness or, at the other end -- when some patients are given only weeks or months to live -- a holistic approach to health and wellness that incorporates psychosocial aspects is necessary: we should, after-all, aim to care for the whole person and not simply treat the disease.5,6

Project Trajectory

In this brief introduction I have sketched the most recent psychosocial and meaning-making research study findings. I then referenced a few existing oncology practice and supportive care guidelines that include psychosocial components and offered (very briefly) some pragmatic barriers healthcare professionals and organizations likely

4 Dr. Virginia Lee offered these insights to me in our discussion over this particular point.
5 Of course, the experience of cancer is a spectrum that contains the experience of chronic or acute illness. For example, there are cancer survivors who ‘beat’ the illness and live the rest of their lives cancer free. However, survivors would also benefit from psychosocial meaning-making interventions, if not, at the very least, to help re-integrate themselves into life post-cancer.
6 For more on treating the whole person see E. Cassell (1991).
face to incorporating psychosocial interventions on a routine basis.

Switching gears slightly, the larger goal of my thesis goes beyond practical barriers – my goal is to present and develop an ethical argument to motivate or, make it a moral imperative for healthcare professionals and organizations to incorporate a particular psychosocial meaning-making intervention into routine cancer patient care. Accepting my conclusion will require relevant healthcare organizations to address and overcome most of the practical and logistical constraints this tool faces.

**Chapter 1**

In Chapter 1 of this thesis I will review in greater detail some barriers to implementing psychosocial care practice guidelines on a routine basis. I will separate these arguments into three categories for simplicity’s sake: practical, theoretical, and bioethical (although it should be noted that each barrier often implicates or involves one or both of the others).

The latter half of Chapter 1 will focus primarily on bioethical barriers and I will discuss the general duty of care and qualify what it means to provide quality cancer patient care. The main point of this chapter is to show that psychosocial meaning-making interventions fall within the bounds of hospitals, healthcare organizations, and healthcare professionals’ capacities and duty of care, more to the point, are necessary for quality cancer patient care under a respect for autonomy rubric.

**Chapter 2**

In Chapter 2 I undertake the theoretical groundwork necessary to advancing a feminist version of respect and support for patient autonomy, which is important to the overall task of arguing for a psychosocial meaning-making intervention from an ethics
perspective. I follow the cue of other feminist philosophers before me and ask questions such as “what sort of self is presupposed by traditional accounts of autonomy”? “What sort of self should be presupposed”? I then identify and concur with a more ‘relational autonomy’, arguing for a socially situated or relational sense of embodied self that underlies patient autonomy.

The second half of Chapter 2 is devoted to considering two feminist accounts of autonomy in light of a particular experience of cancer patient coping with life-altering information. The first account, referred to as a procedural account of autonomy, emphasizes developing skills and capacities for determining one’s values, beliefs, and desires as necessary for autonomy. The second, a substantive account, emphasizes the role certain values such as self-trust and self-worth play in a person establishing what is important to her. After these brief outlines I challenge each account to support a cancer patient in a particular experience of psychological distress - internal conflict. Through this example the limits of a purely procedural account to autonomy and the value of substantive conditions should become clear. However, neither the procedural nor the substantive accounts I outline take into full consideration the important role patients’ fundamental belief systems play in their establishing or re-establishing their autonomous capacities and ability to cope. Acknowledgement and support of this more “existential” work is necessary for a more complete (and acceptable) account of patient autonomy.

Chapter 3

Chapter 3 is primarily devoted to considering a case study of one cancer patient’s particular experience of internal conflict and the effects this conflict has on her capacities for autonomy. This is important in order to situate the philosophical work of the previous
chapter in the clinical setting.

In this chapter I explore various conceptualizations of ethical conflict. In particular, I look at one way that ethical conflict is understood and mediated in the bioethics literature. I argue that this model of conflict resolution does not address the internal process of patients grappling with conflict (their sense of internal conflict), and does not support their capacities for coping with this particular psychological distress (although significant lessons and ways of thinking can be derived from the model). Finally, I re-introduce the psychosocial oncology meaning-making intervention and apply it to the case study at hand. I argue that supporting patients in resolving their inner conflict through participating in the meaning-making intervention is a necessary step to supporting and respecting their autonomy in healthcare decision-making. I thus make the case that the bioethical principle of respect (and support) for autonomy – as reconsidered from a feminist perspective – morally requires this meaning-making intervention’s incorporation into routine cancer patient care.
Chapter 1 Incorporating a Psychosocial Meaning-Making Intervention

1.1 Practical concerns: cost-factors, feasibility, advocacy, and reimbursement and referral

In a review of general barriers to integrating psychosocial care into standard cancer patient care, Jimmie C. Holland, a psychiatrist specializing in psychiatric oncology, identifies four general barriers or difficulties. First, policy makers and healthcare professionals need psychosocial oncology clinicians and investigators to address cost factors and feasibility of interventions outside the research setting in order to prove the effectiveness of psychosocial interventions at an organizational level in a health system or community. It is not enough to prove effectiveness at the patient level, but when discussing how to integrate these practice guidelines into the clinical setting, different kinds of effectiveness studies need to be conducted. Second, advocacy efforts need to be centralized. Psychosocial investigators typically come from a broad range of disciplines (nursing, social work, psychology) and advocates often target their own discipline. This hinders the integration and utilization of psychosocial policy since it often relies on a team effort and demonstrations of multidisciplinary partnerships – where, in a clinical setting, all disciplines are working together towards patient-wellness. Third, cost is a factor, but perhaps this problem is more for the American system where health insurance companies determine who gets reimbursed and at what rate. Finally, doctors are reportedly reluctant to ask patients if they are distressed and, many American oncologists complain that they know of no one to whom they can refer patients in their geographical area (Holland, 2004, pp.452-455). In the following paragraphs I will address each of these concerns in turn.
Cost-factors and feasibility

Despite research that demonstrates the success of interventions in alleviating psychological discomfort or distress, less than 10% of patients are actually referred for psychosocial evaluation and counseling (Holland, 2004, p.452). This signals the need for further research studies, for example, to collect information in ‘real life’ settings or to investigate actual delivery of services in order to produce information which can be used to change health service policy or delivery. Effectiveness studies are needed to determine the extent to which efficacious interventions can be successfully adopted in practice settings. This requires specific attention to treatment costs and to the feasibility of incorporating such interventions into medical settings (Nicassio, Meyerowitz, and Kerns, 2004, p.133). For example, with regards to meaning-making interventions, future research might focus on the healthcare resource costs of allocating specially trained staff to provide the intervention and the time spent to implement the interventions strategies (under some interventions, one sitting of treatment can sometimes last up to one hour for a total of eight 1-hour sessions). Furthermore, the effects and feasibility of hospitals or other healthcare organizations to provide education in order to make the interventions accessible to healthcare professionals and/or to provide their additional training or support in this area are likely to require further empirical study.

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**Advocacy**

Psychosocial clinicians and researchers, by taking on the role of refocusing psychosocial research on cost-factors and feasibility for the medical setting in order to develop strategies to change health service policy and delivery, must take an advocacy position. However, psychosocial clinicians and researchers come from many disciplines and their individual research efforts -- often targeted toward helping their own discipline incorporate psychosocial oncology research -- may limit general motivation for a combined advocacy effort (Holland, 2004, pp.452-3). Overcoming this barrier may require diminishing fragmentation and staging interdisciplinary partnerships including those at the level of professional organization. For example, building partnerships with cancer patients’ advocacy organizations and professional organizations from nursing, social work, and pastoral counseling may prove vital. Similarly, joining all the advocate organizations devoted to specific cancers into one council may help to create a motivating and effective general advocacy movement in order to affect healthcare policy delivery (Holland, 2004, p.453).

The Canadian Psychosocial Oncology Research Training (PORT), a Canadian Institutes of Health Research strategic training program, is already exercising some of these strategies. In order to diminish fragmentation between disciplines PORT, which trains the new generation of psychosocial oncology researchers, is attempting to build partnerships by offering funding to researchers and graduate students across a wide variety of disciplines. Additionally, in effort to combine advocacy, the program’s coordinators host annual meetings in order to foster discussion, disseminate knowledge, and create a sense of interdisciplinary within the psychosocial oncology community.
For example, the program strives to include those typically outside of psychosocial research such as business administrators, management scientists and health policy experts (Loiselle, C. et al, 2004).

Reimbursement and referral

Currently in the United States, psychosocial care faces the priority issue of poor or absent reimbursement for services (Holland, 2004, p.453). For the Canadian experience, budget cuts have decreased the number of social worker and other healthcare professional hours such that patients do not even have minimal professional psychosocial support in rural areas (Stephen, J., & Boyle, M., 1999). Along with or perhaps as a result of financial restrictions, physicians are reportedly reluctant to ask patients if they are distressed. But if psychosocial care were properly funded, this might not be so much of a concern (Holland, 2004).

Addressing these barriers might include bringing together advocacy efforts in order to raise awareness and address the priority issue of insufficient funds for psychosocial care. Similarly, awareness of services, such as the American Psychosocial Oncology Society Helpline, which “seeks to help connect a patient with a mental health professional and provide additional resources to appropriate medical professionals,” may prove useful (Holland, 2004, p.455). For the Canadian experience, the Canadian Association of Psychosocial Oncology (CAPO) has developed national psychosocial oncology standards, seeking to assist cancer facilities, program leaders and practitioners in the delivery of psychosocial care in Canada. CAPO is also in the process of developing further evidence-based clinical practice guidelines (tools often considered benchmarks of good practice by the medical and scientific community), which they hope will increase

awareness of the important and often unmet psychosocial needs of cancer patients.

In conclusion, these practical barriers (cost-factors and feasibility, advocacy issues, and reimbursement and referral) issue concerns for implementing psychosocial practice guidelines and oversight for routine cancer patient care. However, the overall academic atmosphere suggests that these practical concerns may be effectively overcome once further empirical research on cost-factors and feasibility are conducted, and more interdisciplinary support is garnered. Additionally, once resources are in place to support psychosocial oncology professionals and referral lines and interventions are available to address patient concerns and distress, physicians and other healthcare professionals will have more reason to feel prepared in incorporating psychosocial meaning-making guidelines and identifying and caring for patients’ psychological distress.

1.2 Theoretical concerns: the value of a biopsychosocial model of medicine

A second category of barriers to healthcare professionals incorporating meaning-making practice guidelines may stem from more general concerns about the value and place of psychosocial care in clinical practice settings. Namely, it might be argued that the dominant medical model of disease does not sufficiently prioritize the treatment of psychosocial aspects of disease and patient suffering in clinical care.

Medical Model of Disease

Psychiatrist George Engel is noted by the psychiatric community, medical anthropology, health psychology, relationship-centered care and family systems medicine as highly influential in identifying and arguing against the dominant medical model of disease. Engel states:
The dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent of social behavior it also demands that behavioral aberrations be explained on the basis of disordered somatic (biochemical or neurophysiological) processes. Thus, the biomedical model embraces both reductionism, the philosophic view that complex phenomena are ultimately derived from a single primary principle, and mind-body dualism, the doctrine that separates the mental from the somatic (Engel, 2003, p.271).

Historically, psychology is distinct from general medicine. Before 1950 the psychosomatic effects and importance of emotional issues in the etiology of an illness were mainly a concern for the mental health professionals who reported in psychiatric and psychoanalytic journals. The studies these professionals conducted in mental health were often not in collaboration with physicians or surgeons treating patients with cancer, who reportedly had very little interest in these approaches (Holland, 2004, pp.448-449).

George Engel’s dissatisfaction with structural and physiologic explanations of human being’s experience of illness and disease is echoed in the work of others, particularly those in the domain of psychosocial oncology and family medicine.9

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Physician Eric Cassell (1991) wrote *The Nature of Suffering* largely to bring to the forefront the limitations of scientific theory and clinical practice that focused on treating the sick person as a function of treating her disease diagnosis. Such an approach, Cassell argues, does not understand patient suffering at every level of the human condition (from the molecular to the communal) and does not help determine what is the right and good thing to do for that particular patient in order to relieve her suffering (1991, p.64).

Instead of the biomedical model, psychosocial oncology researchers and clinicians support the adoption of a biopsychosocial model as the dominant conceptual framework for the application of health psychology interventions and promotion of an interdisciplinary context (Nicassio, Meyerowitz, & Kerns, 2004, p.135). The biopsychosocial model takes into account the biological factors of disease as well as patient factors, including the social context in which she lives, and the patient’s decision to accept or not accept patienthood status and with it the complementary system devised by society to deal with the disruptive effects of illness. In short, the biopsychosocial model is well situated to address patient suffering at all levels as it includes the relative weight of social and psychological factors as well as biological factors (Engel, 2003, p.278).

Although psychosocial researchers and some clinicians champion the adoption of the biopsychosocial model, some proponents are highly skeptical about whether or not the medical profession, as a whole, is open to expanding the biomedical model to include the psychosocial; this is especially because of the biomedical model’s purported dogmatic status (as discussed in Engel, 2003, p.283).

However, in observations and research on psychosocial interventions for chronic care, James J. Strain finds general medicine open to patients’ psychological issues. He states “the psychiatrist can take some comfort from the fact that, regardless of the extent and nature of their preoccupation with physiological issues, most physicians concede the importance of psychological issues in the onset, course, and outcome of physical disease” (1978, iv prologue). In fact, the largest impediment to physicians and the medical profession’s acceptance of psychosocial care may be, as Strain identifies, the fact that “physicians, largely, do not know enough about psychological care” (1978, iv prologue, italics added).

However, exactly what physicians (and other healthcare professionals) need to know about the psychological in order to accept it as part of a biopsychosocial framework for clinical practice is not something Strain discusses. Are physicians waiting for a time when the psychological (and, presumably, social factors) can be explained in terms relevant to biology? That is, are physicians and other healthcare professionals waiting for psychosocial care to have a proven biological basis and can therefore claim scientific validity (thereby, in reality, privileging and reinforcing the biomedical model)?

The status of the biomedical model is a concern for advocates of psychosocial care. Arguably, if the dominant model of medicine today is biomedical, and Strain is correct to suggest that this model retains its dominance primarily because the medical profession and individual physicians are unaware or are ignorant of psychosocial care interventions, then advocates might focus heavily on addressing practical barriers such as

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10 Recently, in the domain of neuroscience, psychotherapy is seemingly reduced to the biomedical. Reportedly, neurobiology researchers are taking the benefits of psychotherapy more seriously, since they have been able to prove via neuroimaging techniques (such as positron emission tomography, or PET scans) a neurobiological basis for psychotherapy (Fuchs, 2004).
information sharing and educating physicians and other healthcare professionals. Psychosocial advocates and researchers should place strong emphasis on conducting further research on cost-effectiveness and feasibility, and focus on disseminating their findings in order to achieve their goals.

On the other hand, the biomedical model of medicine may represent deeply entrenched values and beliefs about the goals of medicine and clinical practice, which would make focusing on further research and knowledge dissemination an oversimplified solution. It is already the case that despite present efforts on the part of psychosocial researchers, clinicians, and advocacy groups to so far address mounting concerns and develop strategies and guidelines for incorporating policy, their efforts and findings are slow to be recognized in the clinical setting. What might be more effective for psychosocial oncology advocates is a multi-pronged strategy that focuses on addressing practical barriers while also honing specific strategies to address theoretical barriers. Advocates might do well to critically examine and make explicit deeply entrenched values and concepts that motivate and sustain the authority of the dominant medical model of medicine at the exclusion or under-privileging of the psychosocial.

1.3 Bioethical concerns

Besides arguments for practical and theoretical barriers to developing and integrating psychosocial care guidelines for standard cancer patient care, there are also bioethical perspectives that advocates would do well to consider. Identifying relevant bioethical principles that inform clinical practice and critically evaluating them along

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with entrenched goals and values of medicine may lead to more robust argument, or at least more informed understanding of the cluster of barriers, to integrating psychosocial care into routine practice.

**Bioethical principles and duties of care**

In healthcare bioethical principles inform the professional-patient relationship and provide a standard for evaluating guidelines and policies (Munson, 2003). The bioethical principles of beneficence (promote welfare), non-maleficence (do no harm), distributive justice (treat justly), and autonomy (respect self-determination) are the most widely accepted principles which underlie healthcare professionals’ standards or duties of care. These bioethical principles are often reflected in healthcare professional codes and legal literature. In the Canadian province of Quebec, for example, the legally binding Code of Ethics of Physicians of the Collège des Médecins du Québec reflects the principle of beneficence when it states that “a physician’s paramount duty is to protect and promote the health and well-being of the persons she attends to, both individually and collectively” (Collège des Médecins du Québec, 2002, c.2, s.3). In Canadian health law, a case for medical negligence rests on establishing a duty of care and then proving that the duty has been breached. Establishing a duty of care between a doctor and her patient is, according to Gerald Robertson in *Canadian Health Law and Policy* (Downie et al. editors), seldom a contentious issue; as once a doctor-patient relationship is established, a duty of care naturally arises (Robertson, 2002, p. 91).

**Beneficence, non-maleficence, and justice**

Casting the principle of autonomy aside for now (I will return to it later in this chapter), what is expected of healthcare professionals in order that they are perceived to

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12 For an elaboration on these principles see Beauchamp and Childress (2001).
be acting with respect to bioethical principles? We might interpret the bioethical principles of beneficence and non-maleficence as requiring particular conduct related to professionalism (Munson, 2003). Healthcare professionals may exhibit particular personality or personal attributes as well as relevant knowledge and skills that are demanded of professionals as well as important for upholding a duty of care. For example, we can expect healthcare professionals to be cautious and diligent, patient and thoughtful in the conduct of their professions. We may also expect them to pay attention to what they are doing, deliberate about whether a particular procedure should be done and to possess the knowledge and skills relevant to the proper discharge of their duties. Furthermore, we may expect physicians to care for patients by providing them with appropriate treatment and to make reasonable sacrifices for the sake of their patients (for example, discharging responsibilities may involve an interruption of private plans and activities) (Munson, 2003, p.395-398).

Standards of care, which inform a duty of care, are also often connected with such factual matters as the current state of medical knowledge and training and the immediate circumstances or resources and facilities available. That is, the duty of care may be limited by capacities to care. Standards and capacities include: “… the highest possible current medical standards; to this end, he [the physician] must, in particular, develop, perfect and keep his knowledge and skills up to date” (Collège des Médecins du Québec, 2002, c.2, d.5, s.43). This is reflected in legal literature, which establishes a breach in the standard of care when a medical practitioner does not bring to her task a reasonable degree of skill and knowledge which could reasonably be expected of a normal, prudent practitioner of the same experience and standing (Robertson, 2002, p.93). At the more
macro-level (issues related to hospital and healthcare organization priority setting and resource allocation) significant cost-factors might limit the kind or amount of care patients receive. For example, principles of justice may justify hospitals and other publicly funded healthcare organizations foregoing expensive pharmaceutical drug treatments that only benefit a very small proportion of patients even if the treatment is proven to save lives. In these cases, the effects on the small group of patients’ health might be assuaged by the fact that there may be access to alternative therapies including, where available, less expensive or generic drugs or alternative funding sources such as government or pharmaceutical company compassionate release programs.

*Psychosocial care*

Psychosocial care can and should be included in reasonable standards and capacities of care as informed by bioethical principles. Psychosocial care is included in the current state of medical knowledge (see CAPO and Health Canada documents). Furthermore, a thoughtful, diligent, responsible, and skillful physician would be up to date with the overwhelmingly positive psychosocial oncology research findings and judge such care as entirely appropriate for patients who experience life-altering diagnoses such as cancer. Finally, in articulating a general standard for the duty of care, the Canadian Medical Association’s (CMA) professional code of ethics, although not legally binding, explicitly includes psychosocial care as it states that a fundamental responsibility of Canadian physicians is to “provide for appropriate care for your patient, even when cure is no longer possible, including physical comfort and spiritual and *psychosocial* support” (CMA, 2006, italics added).13

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Limitations to providing psychosocial care

There might be legitimate reasons why healthcare professionals are not offering psychosocial care. Physicians might be limited in their capacities to provide certain treatments or care as a result of personal conviction or knowledge. Sometimes a physician’s personal convictions may prevent her from prescribing or providing professional services that may be appropriate for a patient; for example, a physician may be morally opposed to performing abortions. In these cases, however, the physician should at least refer the patient to another physician or facility. In terms of scarce resources, referral is required by Canadian law when a particular test or procedure is not available at a healthcare centre due to cost-containment reasons (Robertson, 2002, p.95).

At the provincial level the Collège des Médecins du Québec, in their professional code of ethics, states that “a physician must, in the practice of his profession, take into account his capacities, limitations and the means at his disposal. He must, if the interest of his patient requires it, consult a colleague, another professional or any competent person, or direct him to one of these persons” (Collège des Médecins du Québec, 2002, c.2, d.5, s.42).

Other times, the medical context is a significant factor in determining what counts as reasonable care or treatment. For example, in emergency situations patients’ physical trauma might be immediately treated while psychosocial support would take a rightful backseat (hopefully to be offered at a later date). Alternatively, psychosocial care may be more highly prioritized in non-emergency cases where patients with illnesses such as

organization and so can only make recommendations for physicians, the ethical code of conduct it outlines is nevertheless instructive on the values that particular members of the body of licensed physicians feel are important to patient care. This may speak to a medical conundrum of sorts; on the one hand the physician community recognizes the psychosocial but their model to treat disease does not include guidelines or methods of addressing and caring for the psychosocial.
Alzheimer’s attempt to adjust to their illness situation and are helped to live out the remainder of their lives in meaningful ways.\textsuperscript{14} Hospitals and healthcare organizations may also have practical or logistical limitations which may or may not legitimately infringe on their capacity to provide psychosocial care such as constraints on time, human resources and education resources. All these limitations may be legitimate reasons to excuse healthcare professionals from providing psychosocial care.

However, the above limitations to capacities to care \textit{should not} warrant excluding psychosocial meaning-making interventions. It is unclear to me what personal bias physicians or other healthcare professionals would exhibit against psychosocial care, which would make referral unnecessary (unless the physician needs to refer because providing the intervention is outside her scope of practice). As for macro-level resource concerns, the financial costs of providing meaning-making interventions would likely not be as high as some new and emerging medical technology or pharmaceutical company drugs and also, with a little training, certain healthcare professionals (especially oncology and advanced practice nurses who have an empathetic nature and already possess good interpersonal skills) would be capable of providing it. Additionally, the population that the interventions would serve is vast (the lifetime probability of developing cancer is 1 in 2.6 women and 1 in 2.3 men)\textsuperscript{15}, not to mention the intervention could be adapted to benefit other patient populations. Lastly, even though there are times when patients and healthcare professionals will address the physical aspects of trauma or disease first, there

\begin{footnote}
\textsuperscript{14} However, most emergency rooms have psychosocial services such as social workers, or psychiatrists that can be called upon to assist with providing comprehensive care to patients. Also, it might be argued that prioritizing psychosocial care in the case of an Alzheimer’s patient may happen when modern medicine is seen to fail in some respect; that is when medical science cannot find a cure or is limited in its physiological management of the disease.
\end{footnote}

\begin{footnote}
\textsuperscript{15} These statistics were gathered from the Canadian Cancer Society’s 2006, Canadian Cancer Statistics document, Table 12. Retrieved June 11, 2006. Website: http://www.cancer.ca/ccs/internet/standard/0,3182,3172_14279__langId=en,00.html.
\end{footnote}
are also times when this option may not always be immediately possible. But waiting for physical treatments may itself create further psychological distress for the patient, which may be allayed by psychosocial intervention.

The point of these examples is to show that general arguments against providing psychosocial care are weak and that there is good reason to incorporate psychosocial care and to hold those ethically (and legally) responsible to provide (or offer) such care.

*Quality patient care*

According to the Romanow Commission’s 2002 Report on Healthcare, *Building on Values: the Future of Health Care in Canada – Final Report*, quality healthcare, which includes providing care that is appropriate and effective, should be the goal we are striving towards. Indicators of quality healthcare include: the needs and expectations of patients and families are being met, patients’ diagnoses by healthcare providers are accurate, and the improvement of the overall health of Canadians (2002, p.150).

Including psychosocial meaning-making interventions is aligned with the Romanow Commission’s call for the improved quality of healthcare, not least because meaning-making interventions can improve patients and family members’ overall quality of life perception. Furthermore, this care is entirely appropriate for the medical setting where the focus (ideally) is on a holistic view of healthcare that goes beyond the physical.

So long as healthcare professionals are providing standard cancer treatment and care (such as chemotherapy and radiotherapy) so too should they provide psychosocial interventions as these have also been proven to benefit cancer patients (and sometimes the latter might be especially valuable when no curative treatment exists). Including meaning-making interventions as falling within the bounds of hospitals, healthcare
organizations, and healthcare professionals’ capacities and duty of care is necessary for quality cancer patient care. That is, it should be understood that physicians are professionally required to provide psychosocial meaning-making interventions and, insofar as professional codes of ethics are morally binding, are under a moral imperative to provide.

*The principle of respect for autonomy*

Although the bioethical principles of beneficence, non-maleficence, and justice all support including psychosocial care, it is the bioethical principle of respect for autonomy that I believe requires psychosocial care the most – but only after the principle is re-conceptualized to capture what is most valuable and enabling of patient self-determination and informed consent.

Tom L. Beauchamp and James F. Childress, in their prominent and influential book, *The Principles of Biomedical Ethics*, discuss personal autonomy as self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice. According to them, the principle of respect for autonomy requires, at minimum, to acknowledge that person’s right to hold views, to make choices, and to take actions based on personal values and beliefs. Included in this definition are obligations to build up or maintain others’ capacities for autonomous choice, acknowledge decision-making rights and enable persons to act autonomously (which involves making sure they are not subjected to controlling constraints by others) (Beauchamp & Childress, 2001, p.63-64). Applying this principle to healthcare, Beauchamp and Childress focus on consent, which they call “the basic paradigm of autonomy in healthcare” (2001, p.65). Building and supporting patients’
autonomous capacities is a matter of supporting their capacities for competent consent, which include the capacities to understand information, make judgments about information in light of their values, to intend a certain outcome, and to communicate freely their wishes to care givers or investigators (2001, p.71).16

Psychosocial care, such as meaning-making interventions that promote and support patients’ self-esteem, hope, optimism, and feelings of self-efficacy, may have profound implications for understanding and supporting patient autonomy in healthcare (Lee et al. 2006). Healthcare situations and illness (including chronic illness such as cancer is sometimes characterized) challenge patients to confront the way they typically understand themselves and their fundamental sense of values, beliefs, and desires.17 Psychosocial meaning-making interventions will allow for patients to regain the capacities necessary for determining what it is they want and for making informed treatment choices.

However, autonomy as conceived by Beauchamp and Childress is not conducive to supporting psychosocial care. First, their conception does not require a healthcare professional-patient relationship necessary for trust and dialogue, a relationship that is no doubt vital for providing psychosocial care. Since their first edition (1979), Beauchamp and Childress’ have been criticized on this point. For example, Katz argues that the disclosure of medical information and consent process needs to involve an exploration of the complex caretaking and being-taken-care-of interaction between physicians and their patients where the focus is more on the joint undertaking than on whether a particular

16 Beauchamp and Childress state “competence in decision-making is closely connected to autonomous decision-making, as well as to the validity of consent” (2001, p.69).
disclosure by the physician has or has not been made (Katz, 1984, p.84). A more complex interaction in light of this focus might involve an autonomy-supportive clinician who helps elicit the patient’s perspective, acknowledging her feelings, providing information, skills training, and resources, providing choices whenever possible, being nonjudgmental, providing a rationale for change in terms that the patient can understand, and supporting the patient’s sense that she can succeed.18

Second, the account of autonomy as explicated by Beauchamp and Childress in their second edition (1983) is not easily amendable to the cancer patient population who, due to the often chronic nature of their disease, struggle with alterations to the body and sense of self over time. In a Hastings Center Special Report, bioethicists Bruce Jennings, Daniel Callahan, and Arthur Caplan argue that the Beauchamp and Childress conceptual framework of autonomy is especially unserviceable to understanding the ethical dimensions of chronic illness “where the nature of the self and the continuity- or discontinuity- of self-identity alters over time amid changes in organic capacity, social circumstances, and in the ability to actively shape and direct one’s life” (1988, pp. 7, 8).

In total, there are five editions of Beauchamp and Childress’ book dating from 1979 to, most recently, 2001. Present criticism, especially from feminist philosophers, is similar to past critiques and, generally, involves questioning the privileged status of the individual, rational patient decision-maker - isolated from the social context.19

Psychosocial care and autonomy

Insofar as autonomy is equated with competence and informed consent, where the

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18 See Epstein et al., 2003, p.47 for further discussion of the relevance of human motivation and change.
focus relies on a patient-provider contract whereby the physician only discloses information in order for patients to make rational choices, those grappling with the psychosocial distress of life-altering diagnosis and healthcare information will not be offered those resources that can offer them significant autonomy support. However, could it be argued that attention to other principles and values, such as having compassion and empathy will promote holistic or patient-centered care that would include psychosocial support? But, notice that more holistic and patient-centered care are exactly what critics of Beauchamp and Childress argue is missing from their understanding of patient autonomy and the physician-patient relationship (refer back to page 29-30 for these criticisms). Katz and Jennings, Callahan, and Kaplan (as well as others I have not made explicit) want to retain the principle of autonomy and imbue it with more ‘deep’ or complex understandings of the physician-patient relationship and patient decision-making process. By extension, once healthcare professionals have a richer understanding of patient autonomy and, hence, of what can support patients’ autonomous capacities (where this includes ability to cope with life-altering diagnosis), the value of psychosocial meaning-making interventions within this bioethical framework will become clear.

1.4 Conclusion
Under Jennings, Callahan, and Kaplan’s interpretation, the principle of autonomy (such as Beauchamp and Childress outline), is decidedly individualistic, where self-identity, autonomy, and interests are conceptually prior to and independent of the encounter with illness and the experience of participation in the care-giving process. For these reasons they argue that the autonomy paradigm needs substantial revision (1988).
Using philosophical theory to re-conceptualize and engage with the principle of respect for patient autonomy is an important endeavour as bioethical principles may direct healthcare procedures and policies, and inform goals and duties of care (Munson, 2003; Jennings et al, 1988). Furthermore, the principle of autonomy is well-suited to capturing what is important about providing psychosocial care since the benefits of psychosocial care are to establish or re-establish patient capacities for self-determination and informed consent. Insofar as I and others would like to see psychosocial meaning-making interventions incorporated into routine cancer patient care, re-conceptualizing autonomy, along with addressing the more pragmatic (i.e. practical and, to some extent, theoretical) barriers to integrating a meaning-making intervention into routine cancer patient care, seems a reasonable course of action.

In this chapter I gave an overview of the practical, theoretical, and bioethical barriers to integrating psychosocial care on a routine basis. Focusing on the bioethical barriers, I argued that bioethical principles inform healthcare practice and policies, and as such, they are integral to understanding standards and healthcare professionals’ duty of care. The duty of care as informed by bioethical principles supports psychosocial care. This is especially true of the principle of respect for autonomy but only when it is re-conceptualized. The principle of autonomy needs to recognize the value of the patient-provider relationship conducive to psychosocial support and also the importance of supporting patients in determining what values, beliefs and desires are most important to them in the context of life-altering information and chronic illness. My discussion of the bioethical principle of autonomy in the next chapter of my thesis will philosophically engage the criticisms put forth by Katz and Jenning’s et al. as well as engage feminist
critiques. My goal is to re-conceptualize the principle of respect for autonomy in order that it is more conducive to supporting cancer patients’ self-determination.
Chapter 2 Exercising Autonomy, the Self and Navigating Internal Conflict

Respect for patient autonomy is widely regarded as an important principle of medical ethics. It is also widely regarded that the sense in which it was asserted by Tom Beauchamp and James Childress (1979) in the first edition of their influential book *Principles in Biomedical Ethics*, is in keeping with the liberal conception of respecting individual free and rational action. This conception stresses a non-interference attitude of healthcare professionals that has been subsequently criticized by some as being unsupportive to persons who might not possess the independent rationality to make choices and judgments. 

Although Beauchamp and Childress have revised their conception of autonomy over many editions and today assert something that is more sympathetic to their critics, the liberal ideology behind its inception arguably still holds sway in the medical setting today.

In the previous chapter I outlined some practical, theoretical, and bioethical barriers to incorporating psychosocial meaning-making interventions into routine cancer patient care. I concluded with a mind to focus additional analysis on the bioethical principle of respect for autonomy, deeming it an important and influential principle, although I agree with some critics that it is in need of revision and re-conceptualization.

In this chapter I re-conceptualize the dominant autonomy paradigm that conflates autonomy largely with patient competence and the ability to rationalize and navigate options and information, and exercise choice. I then delve into conceptions of self that motivate patient autonomy under the traditional view and concur with an alternative,

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feminist conception that appreciates a more relational and socially situated sense of self whose values, beliefs, motivations, desires, and goals are influenced by her embodiment and social context.

My next move is to consider two alternate accounts of autonomy. First I consider a procedural account offered by feminist philosopher Diana Meyers, who stresses autonomous people are those who are able to exercise various skills or capacities for self-determination. I then consider more substantive accounts offered by Paul Benson and Carolyn McLeod and Susan Sherwin. These latter accounts stress persons having a sense of self-worth (Benson) and self-trust (McLeod and Sherwin) as necessary conditions for autonomy.

Finally, I challenge both accounts (procedural and substantive) to support a cancer patient in the particular experience of internal conflict and transitioning values. Through this example the limits of a purely procedural account to autonomy and the value of at least these substantive conditions should become clear. Furthermore, the important role of patients’ coping with their psychological distress, and in re-integrating, affirming or denying a fundamental system of wants, values, beliefs, goals and preferences for action should also become clear. This latter point, which neither the procedural nor the substantive accounts I outline take into full consideration, is necessary for a patient to be considered autonomous.

2.1 Patient autonomy re-configured

In a passionately written and thought-provoking article, Jennifer Beste criticizes some physician writers who hold that patients’ experience of pain, suffering, shock, fear,
and anger prevent them from ‘taking in’ all relevant information. Consequently, these emotional states can impair patients’ autonomy or ability to make informed and carefully reasoned choices about treatments (Best, 2005, p. 217). In response, Beste argues against these writers and attempts to expand the concept of autonomy in light of her observations and experience of having spent an eighteen month ethics internship in an oncology bone marrow transplant unit.

During her internship, Beste becomes especially close to one young woman, Karen, who wages what Beste derisively labels her ‘war against cancer’ (2005). Beste sympathetically follows Karen’s care and is privy to her personal experience of disease, suffering, and depression. After forming a strong attachment to Karen and personal interest in her well-being, Beste asks the primary care providers why Karen has not been told the truth about her dramatically declining health. The attending oncologist remarks that because of Karen’s depression, she does not have the capacity to appreciate information and be objective about her situation. Karen’s personal autonomy is thus overturned by a paternalistic care-giver team, who decide it is in her best interest to receive aggressive treatment in the ICU. The distressing consequence, Beste notes, is that Karen dies an isolated death on the bone marrow unit, without a choice to spend her last months or even days with less invasive treatment at home in the company of her two small children and husband (2005).

Often in oncology the framework of patients waging a war against cancer equates hope with beating cancer; it equates hope as hope-for-a-cure (Beste, 2005, p. 227). Beste argues vehemently against this framework, arguing it undermines patients’ ability to be self-determinate and autonomous. Instead, Beste wants to reconstruct the narrative of
hope in relation to what is most valuable to the patient in order for her to live a meaningful rest of her life (2005, p. 229). Ultimately, and in defense of Karen’s autonomy, Beste offers the following two points, which we may take as instruction for thinking about how to support patient autonomy:

1) Even though patients may experience pain, suffering, shock and trauma that may compromise patients’ ability to comprehend, the proper response is not to declare these patients incompetent. Rather, healthcare professionals must make extra effort to support patient’s capacities for autonomy.

2) Emotions should not always be seen as an obstacle to autonomy; they may play an integral role along with reason in making autonomous choices. Instead of seeing the experience of severe illness and suffering as robbing patients of their autonomy the experience should be viewed as part of patients’ coping with life-altering information (2005, p. 229).

Taking Beste’s claims seriously entails shifting respect for autonomy language to a support for patient coping with life-altering information and transitioning values discourse. This might involve, in Karen’s case, healthcare professionals’ respecting and supporting Karen’s decision to shift the meaning of hope as beating cancer to hope as having hospice care in the family home in order to live a meaningful life in spite of declining chances of survival (2005, p. 222, 227).

Beste is not alone in challenging traditional understandings of patient autonomy as competent and rational decision-making or informed consent. Feminist philosopher Carolyn Ells reconsiders the principle of respect for autonomy from a disabled persons’ standpoint, arguing that the principle, as conceived by bioethicists Tom Beauchamp and
James Childress, doesn’t acknowledge the dynamic nature of self-identity and the boundaries of the body (2001, p.610). As Ells makes clear through disability narrative, philosophical theories of autonomy, which inform clinical practice, would do well to reconsider autonomy in light of an embodied self situated within inter or dependent relationships, and as the construction of personal meaning of one’s life within social and physical limits and conditions (2001, pp. 608-615).

Medical ethicist and philosopher David C. Thomasma similarly critiques the biomedical language of autonomy as centering on individualism and abstract decision-making and informed consent. He argues these concepts are removed from the particular and practical realities of patients’ medical decision-making where patients have different ways of being self-determinate that traditional respect for autonomy does not acknowledge and appreciate (1995, p.14). For example, one patient may cope with the news of serious illness by putting into place very “autonomous – appearing” steps, where her actions are clearly calculated with respect to overriding goals and values. At the other extreme might be a patient who, when confronted with serious illness, abruptly turns her life over to God and says that it is God’s will that she dies. At first sight, Thomasma suggests that “the latter patient’s action and decision-making might not seem reflective of autonomy or self-determination under a traditional view since it looks like she resorts to extreme dependency on some external source of meaning” (1995, p.15). However, Thomasma argues that “both patients’ responses to serious illness may be reflective of autonomy as both are coping behaviours that reintegrate the healthcare situation with a structure for personal integrity” (1995, p.16).

Autonomy, for Thomasma, is more a feature of individual identity and integrity,
which includes having a picture of one’s future life plans and making an assessment of risks and opportunities one will likely encounter in the present and future. Respect for autonomy should include “respect for patients’ coping behaviour and strategies as these tend to preserve or are in keeping with one’s personal survival and integrity” (Thomasma, 1995, p.16). It is not simply the ability to rationalize and choose between options that are required for autonomy. At the very least it matters which choices we prefer, and those preferences are imbedded in personal meaning structures, developed or influenced by a self situated within relationship and community contexts.

2.2 The self and autonomy

Some feminist philosophers and bioethicists employ the language of “relational autonomy” to capture the importance of relationships and social context in forming one’s sense of self and preferences. A relational and socially situated self stresses that the interests we have, values we endorse and goals we pursue are influenced by who we relate to, what time and place we occupy in society and what social resources are available. A general aim of many feminist philosophers is to shift dissatisfactory notions of the self, which underlie traditional autonomy and replace it with this richer, more informed understanding of the self and a corresponding understanding of autonomy. Autonomy in light of this social self would take context and relationships into account in a significant way.

The social self and the possibility for autonomous agency

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Some might be tempted to argue that the very concept autonomy is incongruent with selves identified as socially constituted because “for every value, plan, or project endorsed by the self, there is a set of social influences that can account for why one makes the ‘choices’ one does” (Barclay, 2000, p. 54). If that were the case, it seems to follow that one is not the cause of one’s own actions rather one’s actions are caused by antecedent social influences. Yet, we need not discount the idea of autonomy by favouring a social constructionist view. As Linda Barclay writes, “autonomous agency does not imply that one mysteriously escapes altogether from social influence but rather one is able to fashion a certain response to it” (2000, p. 54). Similarly, writing on patient autonomy in healthcare, Susan Sherwin reminds us of the continued importance of the individual in relational or socially situated understandings of self and autonomy. She states “our attention to social and political contexts helps deepen and enrich the narrow and impoverished view of autonomy available under individualistic conceptions, but it does not support wholesale neglect of the needs and interests of individualism in favor of broader social and political interests’’ (Sherwin, 1998, p. 39).

The social self as embodied self

As acknowledged by Ells in her narrative on autonomy and disability the bodily experience of illness or impairments can have profound implications for one’s sense of self-identity (2001, p.610). Illness more generally brings the experience of the body into the forefront of our consciousness and with this can bring alterations to our sense of self-identity. For example, a woman who has just been diagnosed with ovarian cancer and is facing the likelihood of infertility might come to question her self-identity insofar as it relies on her becoming a mother and her anticipation of fulfilling this role. Additionally,
if chemotherapy treatments were to be pursued (as is commonly the case) the woman might come to experience the physical fatigue and nausea often associated with chemotherapy as threatening her capacity to continue being the sort of woman she prides herself as being. The treatments might undermine her capacity to remain as physically active as she was before her diagnosis and treatment, as well as leave her very little energy to continue being the main financial supporter of her and her partner's household (where these activities and responsibilities are ones that she gladly embraces). Indeed physical activity keeps her mind clear so that she can focus on managing her business and other activities most effectively. With the embodied experience of cancer and cancer treatment come alterations to the woman’s sense of self-identity and has implications for her autonomy because her sense of values, beliefs, and desires that inform her goals and actions are being thrown into question. The woman's sense of herself as the primary financial supporter, physically active, and as someone who deeply desires to become a mother will be thrown into question along with the goals she sets for herself and what others expect of her.

2.3 Exercising patient autonomy
As our appreciation of the self that underlies patient autonomy broadens and is enriched by our knowledge of its relationships, embodied experience, and social context, so should our idea of what exercising autonomy entails (and of what support for patient autonomy entails). Often accounts of exercising autonomy are separated into two. Some emphasize the process of critical reflection and capacities for autonomy (procedural theories), while others articulate specific capacities or character traits as necessary for
autonomy (substantive theories). Most of the latter theories contain procedural aspects, although the processes may vary. In the sections that follow I provide a brief review of the procedural and substantive autonomy literature.

Procedural: Autonomy Competency

A procedural account to autonomy is typically content-neutral in the sense that it doesn’t matter what preferences, values, beliefs, or desires are held by a person, only that they are arrived at in a certain way, according to a particular procedure.

Feminist philosopher Diana Meyers is well known for her procedural account of autonomy that allows for a person to transform her goals and values as she develops ‘skills’ necessary for determining what it is that she really wants. For Meyers, autonomous people are those who are able to engage in critical reflection. This includes identifying what they want, care about and believe, acting on their authentic desires and knowledge, and re-directing themselves if they make an error in acting (Meyers, 1989; 2001). Being autonomous means employing an array of skills constituting ‘autonomy competency’. Some of the skills that Meyers values as conducive to self-determination include “being introspective, having well-established communication, memory, and imaginative skills, as well as analytical, volitional and interpersonal skills” (2001, p.742). Additionally, Meyers allows for degrees of autonomy; one may be minimally, medially, or fully autonomous depending to what extent one is able to exercise her autonomous capacities (Meyers, 1989).

Adopting a procedural account like Meyers, which emphasizes developing and/or restoring skills for autonomy competency, may help patients in maintaining or re-establishing their autonomy in the context of life-altering and traumatic healthcare...
situations. In my earlier example of the woman diagnosed with ovarian cancer, the
diagnosis, amongst other things, challenges her belief and desire that she would become a
mother. Suppose that previous to her diagnosis the woman’s decisions and actions were
consistent with this desire (e.g. she made career choices that allowed her the most
maternity leave were she to get pregnant; she made financial decisions that allowed her to
save money in order to prepare for a child). After the diagnosis, the woman is unsure
about how to continue living her life, not being able to engage in the world in accordance
with the same values and beliefs as before. One might distinguish fundamental values,
beliefs, desires from less fundamental. For example, pre-diagnosis, the woman’s
fundamental beliefs might have included the conviction that she is personally responsible
for what becomes of her. With enough effort, perseverance, and audacity she should be
able to overcome most obstacles in order to get what she wants. Yet by engaging in
critical reflection she might revise or reaffirm her sense of self-identity and retain or
regain her autonomy by exercising skills to reconfigure her fundamental values and
beliefs in light of her situation. The woman might relax and attribute more of her life
events as a result of ‘luck’ or ‘chance’ and therefore out of her purview. As a result, the
woman might re-evaluate her life in a more relaxed manner and come to see a purpose for
considering other options such as adopting a child or she might decide that she really
does not want to become a mother at all. She might consider these options and these
values in conjunction with other relationships of importance to her. In these scenarios
and possible others the woman’s fundamental and less fundamental values, beliefs, and
desires may be reconfigured in light of her present healthcare situation. 24, 25

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24 I will talk more about the distinction between fundamental and less fundamental beliefs and desires later
in this chapter.
**Substantive: self-worth and self-trust**

Substantive theories of autonomy typically put limits on the kinds of beliefs and desires a person must have in order to be considered autonomous. Paul Benson offers a substantive theory when he argues that persons must meet the condition of having a sense of self-worth or competence in order to be considered autonomous (Benson, 1994). Under Benson’s view, a person must believe she is worthy and deserving of making appropriate choices for herself in order for her to be considered an autonomous agent.

Carolyn McLeod and Susan Sherwin offer a somewhat different substantive condition for autonomy than Benson. They argue that autonomous persons must have a sufficient amount of self-trust that allows them to trust their judgments and ability to exercise choice and act on their decisions (McLeod & Sherwin, 2000).

Although McLeod and Sherwin argue the condition of self-trust as distinct from self-worth, the two character traits are closely connected and may implicate each other, especially in the context of oppression. Oppression interferes with autonomy as it can cause self-distrust in the agent’s decision-making skills by depriving her of sufficient opportunities to develop and exercise those skills:

> When a group is oppressed the society at large operates as if that group is less worthy and less competent than others, and devalues its members.

> Members of oppressed groups may then internalize these attitudes…leading them to doubt their own personal worth and

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ability to make appropriate choices” (McLeod & Sherwin, 2000, p. 262-3).

Although Meyers, Benson, and McLeod and Sherwin’s work are all helpful in articulating what exercising autonomy might require the challenge is to apply these philosophical theories to the practical realities of the healthcare setting and, for my project, the particular realities of the cancer patient’s experience.

2.4 Ethical conflict: a challenge to procedural and substantive accounts of autonomy

Specific realities and challenges to patients’ autonomy might include the experience of ethical conflict or transitioning values, which strain personal integrity structures that give overall guidance and meaning to their life. These challenges seem particularly salient to patients encountering traumatic and life-altering healthcare experiences and/or chronic illness such as cancer.26

There are at least two sorts of ethical conflict that exist in healthcare: conflict that is external or internal to the patient. External ethical conflict generally arises when there is disagreement between family members, between patient and family members or between healthcare professionals involved in making healthcare decisions regarding the patient’s treatment and care. This conflict involves competing truth claims; that is, whose perspective is ‘right’ and should govern decisions made about patient treatment and care. Here the ethical conflict exists externally to those participating in the disagreement; it arises outside of the expressed wishes of each participant and in the

space where the two or more in conflict confront and disagree with each other. In
external ethical conflict the patient (or surrogate decision maker) already seems to have
established a sense of what she wants. The opinions and decisions that reflect these
desires are challenged by healthcare professionals who have different opinions about
what is best. Among the challenges in these situations is respecting a patient’s already
established autonomous capacities and skills.27

Internal ethical conflict - or perhaps better understood as simply internal conflict -
is located internal to the patient herself. Internal conflict sometimes manifests itself when
a patient is unable to determine what it is that she really wants with regard to her
treatment and care. The patient experiences some internal discrepancy or conflict and is
unable to identify with what she truly desires. Internal conflict may be the result of
unresolved trauma to a patient’s fundamental belief system or when patients are caught in
the midst of transitioning values caused by receiving information that shatters that which
previously structured or provided the framework for understanding the self and the self in
the world.

A fundamental belief system such as I am describing (as opposed to standard
values, beliefs, or desires) might be likened to highest principles as articulated in a split-
level account of autonomy identified by Marilyn Friedman.28 In Friedman’s account

27 See Franco Carnevale’s article for elucidation and a case study of what I describe as ‘external’ ethical
Nursing Ethics, 12, 239-252.
28 Split-level accounts of autonomy stress that motivation is only one’s own when endorsed by critical
assessment and when they are in accord with one’s higher order principles. My account of fundamental
beliefs does not agree with general split-level accounts where higher order principles are autonomy-
conferring and action in accordance with these principles equals a truer, more authentic self. Rather, I tend
to concur with Marilyn Friedman that there is an integration of lower level and higher level desires. As
Friedman writes; “highest principles must be assessed for their fit and appropriateness in light of what
guides and motivates a person at the lower levels” (1986, p. 33). For further discussion see Friedman, M.
highest principles are “the most general and all-encompassing principles, providing articulated criteria for assessing all other standards and motivations” (1986, p. 32). For example, the woman with cancer and others like her, prior to receiving the cancer diagnosis, likely had standard beliefs about her mortality and how to live a reasonably long and healthy life. These beliefs were upheld by deeply entrenched beliefs (fundamental beliefs or highest principles) about the verity and puissance of human biology and modern science. Upon receiving her diagnosis the woman’s fundamental beliefs were shattered along with her more standard beliefs about what actions lead to a healthy life as she was physically active and followed a nutritiously balanced diet, yet still got sick. Lacking her fundamental perspective all the other values, beliefs, and goals that she set for herself and relied upon it were thrown into question as well as her confidence in her ability to establish true and meaningful belief frameworks.

The experience of internal conflict can be overwhelming and mark a time of high anxiety or psychological crisis. Patients’ distress may elevate when they are faced with the further pressure and expectation to use knowledge about what is important to them in order to make treatment and care decisions. While in the midst of a fundamental values crisis (receiving value or belief-shattering information) or transitioning values (recognizing ineffective belief systems and re-evaluating them or erecting new ones) the patient is yet without a newly established fundamental guiding framework to structure some or all of her perceptions and prioritize her desires. When pressed with the further imperative of having to make decisions about how to proceed in healthcare treatment decisions, the patient may experience deep, internal division or ambivalence. Lacking guidance and support in navigating and coping with her experience, the patient might feel
hopeless and disempowered in her ability to transition and exercise her autonomous capacities in order to arrive at a renewed sense of what is important to her.\textsuperscript{29}

\textit{Internal conflict and a procedural and substantive account}

Internal ethical conflict as a result of receiving a fundamental belief-shattering diagnosis or piece of medical information has repercussions for patients’ autonomous agency that may not necessarily be solved by simple exercising of skills and capacities for autonomy as indicated by a purely procedural account like Meyers. First, even if patients are capable of exercising skills for autonomy it doesn’t mean that they will come to any determinations in order to inform their actions. Patients may become stuck in a continual cycle of exercising skills for determining what it is that they truly value, believe, and desire without ever realizing or developing a sense of what is important to them. Instead of finding a solution to their conflict through exercising skills and capacities, they may feel intense uncertainty, loss of control, and increasing levels of despair and insecurity. This may lead to a breakdown in capacities for autonomy. The other danger might be that the patient feels unable to exercise her capacities at all. Therefore, instead of getting stuck in a cycle she might never even enter the cycle. Lacking a fundamental framework to guide the resolution of inner conflict and direct patient perception to those values, beliefs, and desires that fit within her framework, patients may continually exercise her autonomous capacities with no end in sight. It is conceivable that a patient in this predicament left unsupported could completely lose faith in her autonomous capacities and follow her despair down into a spiral of self-defeat.

\textsuperscript{29} At this point there might be a tendency to refer to a patient having such an experience as a ‘traumatized patient’. But, I think we should resist this temptation. Labeling the patient as traumatized only categorizes the patient as a victim and does not empower her to challenge her distress (perhaps with the aid of healthcare professionals and family support).
whereby she attempts less and less to exercise her capacities and establish a sense of what she wants and at some point abandons herself as a worthwhile project altogether.

Substantive conditions such as developing or supporting a patient’s sense of self-worth and self-trust may help a patient to feel worthy of entering into the cycle of critical self-reflection and also of trusting her judgment when she arrives at certain values, beliefs, and desires she feels to be most representative of her at the time.

*Identification and a substantive supplement to procedural autonomy*

Identifying with, or reflecting on “who one is” is important for autonomy. According to Marilyn Friedman, someone’s identity reflects her deeper, wants, desires, cares, concerns, values and commitments, and is implicated in her autonomous behaviour. One exhibits a certain degree of autonomy when her behaviour is partly caused by her reflections on and reaffirmations of her deeper wants and commitments. Wants and values are “deep”, according to Friedman, in part, “when they constitute the overarching rationales that an agent regards as justifying many of her more specific choices” (2003, p. 6).

An account of exercising capacities for autonomy must be more than simply procedural if it is to recognize internal conflict challenges to autonomy and help patients transition their fundamental values, resolve their ethical conflict and incoherence amongst their beliefs and avoid a manifest breakdown in capacities. Although Meyers identifies the inability to adjudicate intrapersonal conflicts as autonomy threatening, she does not explicitly address what characteristics a person might exhibit in order to *identify* with new values or reinstate her old values. Substantive conditions such as having a sense of self-worth and self-trust may be necessary for identifying with what one wants,
but not sufficient – as simply possessing the conditions themselves do not create the bond of identification but only seem to create the conditions for its possibility. That is, possessing self-trust and self-worth may make persons more resilient in their quest to determine what is important to them but by themselves do not explain why some things over other things are more important for re-integrating shattered dispositions in order to live a meaningful life.

*Structural theories*

McLeod and Sherwin, in arguing for degrees of self-trust for autonomy, recognize the role identification plays. They argue that there are instances where it is reasonable for a person to lack self-trust, most notably, in situations where a person lacks relevant knowledge and information to make decisions (if I am a philosopher, then having a certain amount of distrust to make decisions related to engineering may be well founded). Lacking self-trust in such situational areas does not mean that philosophers in engineering contexts do not have autonomy. The difference for autonomy “depends on whether or not the person identifies her or himself with or highly values the area in which self-trust is lacking” (McLeod and Sherwin, 2000, p. 264). It is within those areas where self-trust matters for autonomy that a person must be able to identify with or form higher order beliefs about what one wants or values.

Structural theories to autonomy, along with substantive conditions may supplement procedural accounts. Under structural theories, autonomy requires more than exercising capacities for self-reflection or having self-trust and self-worth, but also requires that “hierarchically ordered elements of the self exhibit a certain kind of structural organization” (Mackenzie and Stoljar, 2000, p.14). That persons have
fundamental desires by which they order other desires reflects a sort of organization that structural theories espouse. This may be seen in my example of the woman who received an ovarian cancer diagnosis as she structured her standard beliefs about what leads to a healthy life on her more fundamental beliefs about human control over biology and disease. The assumption here is that she identified with those fundamental beliefs and standard beliefs such that she felt they were authentic of her and felt they rightly were her own. This sort of structural theory needs to be more fleshed out since there is the difficulty of explaining primary identification, or those deep values, wants, and desires that a person first developed or came into possessing with which she structured all later reflections, affirmations or re-affirmations.

I believe that a certain structure matters for cancer patients to regain their autonomy in the face of internal conflict; however, I will develop this idea further in the proceeding chapter using a case study. For the present I would like to consider, since I have outlined procedural and substantive accounts to autonomy in the beginnings of this section, how a structural notion of autonomy accords with what I have already outlined. I have already said that a purely procedural account to autonomy is not enough for one could have full use of her capacities but not identify with any values, beliefs, or desires these capacities generate (which could lead to hopelessness and, ultimately, a manifest breakdown in capacities). Introducing substantive criteria in order to supplement Meyers’ procedural account is useful as it may at least help patients avoid a manifest breakdown in capacities by protecting them, to various degrees, from spirals of self-defeat. Additionally, one may argue that the ability to establish or re-establish a system of beliefs that gives meaning to one’s life requires having certain character traits or
attitudes towards oneself that makes this project possible. Exercising autonomy might, for example, require knowing oneself as worthy of undertaking such a project, or trusting oneself to make good and reasonable judgments in light of having already determined, through critical reflection, a set of values, beliefs, and desires. Note that if it is correct to include these substantive conditions for autonomy it would not necessarily be in place of a procedural requirement like Meyers’ exercising of skills; rather, the former conditions supplement the latter capacities. Note also, that autonomy under this articulation still admits to matters of degree. One may be minimally, medially, or fully autonomous to the extent that she is able to exercise her capacities and exhibit strengths of character.

Evaluating the utility of internal conflict

Returning to the concept of internal ethical conflict, some might argue that this state itself does not necessarily compromise autonomous agency because it does not always constitute a manifest breakdown in the capacity for critical reflection, which would be incompatible with procedural accounts of autonomy (Stoljar, 2000, p. 105). Natalie Stoljar and Cheshire Calhoun have both defended internal conflict (or in their cases, internal incoherence) when it results from minority groups’ reflective awareness of competing desires associated with different norms or groups to which they are a part. In these examples acknowledging competing desires is a first step to identifying with who one is (and so maintaining integrity of person) and/or towards liberating oneself from oppressive norms. According to Stoljar “a proper exercise of critical reflection requires acknowledgment of the incoherence inherent in one’s circumstances” (2000, p. 105, italics added).

Stoljar and Calhoun’s intuition seems correct, and highlights the need for a more
substantive account to exercising autonomy than Meyers’ if one wants to take seriously the challenges to patients’ coping with internal conflict. Healthcare professionals’ responses to patients having difficulty identifying with their desires but do not yet manifest a complete breakdown in capacities should not be hands-off, but rather a care team effort whereby the professionals offer support for patients’ autonomous capacities and coping process.

2.5 Conclusion

In this chapter I have discussed concepts of relational autonomy, the social self, and theories of autonomous agency (procedural and substantive accounts as well as introducing a structural account). I have shown the difficulties these accounts face to supporting a patient in resolving her internal conflict in order that she is in a better position to make healthcare treatment decisions that are aligned with her fundamental values, beliefs, and desires.

Although not explicitly discussed in the nursing research and psychosocial oncology literature, the psychological distress to which the meaning-making intervention is directed will likely support patients in resolving their internal conflict and restoring their autonomous capacities. The intervention is directed at helping patients manage their shattered assumptions about the world and transitioning values – all very similar symptoms of patients who are caught in internal conflict. Therefore, if healthcare professionals respect a feminist conception of relational autonomy, which requires support for patients’ capacities and skills for autonomy (which would include substantive, procedural, and structural elements) then the meaning-making intervention, which has positive effects for cancer patient coping (coping itself a skill for autonomy) can be
utilized to help a patient in resolving internal conflict.

The final chapter will illustrate how a meaning-making intervention can be applied to help a cancer patient overcome her internal conflict and restore her autonomous capacities. This is important for arguing the necessity of providing the meaning-making intervention under an autonomy framework.
Chapter 3 Cancer Patient Internal Conflict: the case for a meaning-making intervention

In this chapter I will demonstrate how internal ethical conflict is a very real concern for cancer patient autonomy and how the meaning-making intervention can help to restore patient autonomy. In doing so, I will begin with a brief case study of a particular cancer patient’s experience of having to make a decision regarding her course of treatment, highlighting the crippling effect her internal ethical conflict has on her sense of autonomous agency. Following this I consider how one bioethicist has conceived ethical conflict in the healthcare setting in order to further highlight the need to address internal conflict. After pointing to some limitations of the former account I enter into discussion of a psychological account of inner conflict offered by Harry Frankfurt and apply his analysis to the case study. Although Frankfurt does not explicitly link his account with autonomy, one may easily see that it is extendable and has implications for autonomy. I then offer a more robust conception of patient autonomy by incorporating Frankfurt’s deconstruction of inner conflict with a feminist account. Through my analysis it will become clear how mediating ethical conflict presupposes not simply the reconciliation of internal inconsistencies but also support for patients’ abilities or capacities. More than this, I argue that supporting patients in resolving their inner conflict is a necessary step to supporting and respecting their autonomy in healthcare decision-making. I thus make the case that meaning-making interventions, which have this effect, should be offered as part of routine cancer patient care.

3.1 Case study: cancer patient experience of internal conflict

Sara is a young woman recently diagnosed with ovarian cancer and is given the whole gamut of treatment options by her oncologist, which includes chemotherapy and
radiotherapy treatments. After completing the chemotherapy treatments Sara must now make a decision about whether to go ahead with radiotherapy treatments. Radiotherapy is not required to rid her cancer (which the chemotherapy has already supposedly done) but is strongly encouraged to reduce the likelihood of the cancer recurring. Deeply torn between deciding to go ahead with the radiotherapy (as favoured by her physician) or not, Sara has confessed to a nurse close to her care that she feels inwardly divided and therefore incapable of making a decision. The part of her that she refers to as ‘the logical’ reasons that she should follow her physician’s advice and complete the radiotherapy; however, another part of her, what she refers to as ‘the intuitive’ is pushing her to stop, believing the chemotherapy treatments to be enough. The experience is crippling Sara; she feels frustrated and depressed and is unable to make or commit to any decision related to this issue because doing so, she feels, means silencing or denying the half of her that disagrees.30

Generally, internal ethical conflict may act as a barrier to autonomy or acting authentically primarily when it restricts patients from feeling capable of determining, identifying or endorsing with what they really want or in making decisions that are aligned with these desires. As such, internal conflict may interfere with capacities for autonomy. Internal ethical conflict, taken to the extreme may create a sense of despair, loss of control, or apathy in a person further inhibiting her from accessing her true

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30 This case is a composite case inspired, in part, by Virginia Lee’s research. For example, one patient as part of a qualitative study asking patients to describe their coping process (Virginia Lee, McGill University, not yet published) described her immediate healthcare decision-making self as a “phantom” of her older, more “real” self. This patient felt similarly torn and disconnected from the fundamental beliefs she used to hold so strongly.
Approaching ethical conflict

Ethical conflict often presents itself in healthcare settings and contexts as disagreement between healthcare providers, and patients or family members involved in making decisions regarding patients’ treatment and care. These parties are seen as competing for whose perspective should govern what happens. For example, it might be the case that a mature child acting as surrogate decision maker of a comatose elderly parent expresses a desire to end all life-sustaining treatment for her parent. Her desire might conflict or disagree with the desires expressed by healthcare professionals participating in the elderly patient’s care. In this situation and others like it the ethical conflict arises not within the expressed wishes of each participant but in their interaction, where the two sides (or more) confront and disagree with each other. In this thesis, I characterize such conflict as “external conflict”.

In his thoughtful work “Ethical Care of the Critically Ill Child: A Conception of a ‘Thick’ Bioethics” Franco Carnevale directly addresses how a bioethicist should approach resolving or mediating ethical conflict between parties, focusing on when the care involves a critically ill child. Carnevale urges an interpretive framework for understanding ethical conflict in the healthcare setting, one that views each party’s moral claims as grounded upon culturally relevant conceptions of morality. An interpretive approach appreciates that each person’s healthcare decision-making is influenced by particular perspectives and understandings, which are derived from culturally and

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temporally embedded experiences. All of us are immersed in cultural communities, which themselves identify social valuations of what goods and ends of life represent the standards by which our desires and choices are judged. Each person then takes the knowledges and practices of the community she considers significant and derives identity, shape, and meaning for her life (Carnevale, 2005, p. 242). A person’s moral outlook is informed from those cultural contexts she judges significant. In mediating ethical conflict, where various moral outlooks diverge or disagree Carnevale argues the bioethicist should use this interpretative framework for understanding and draw upon ‘thick’ accounts of the moral discourses at play. The bioethicist then acts as mediator of the ethical conflict, seeking to ‘fuse moral horizons’ in reconciliation or ‘rapprochement’ – a process argued for by Charles Taylor and Carnevale adapts to the healthcare setting. Under the rapprochement approach to ethical conflict resolution the bioethicist “facilitates a complex conversational process among decision makers with the aim of reaching decisions that are as consonant as possible with each participant’s own moral framework within the given circumstances” (Carnevale, 2005, p. 245).

Carnevale’s description of how moral outlooks arise within cultural contexts and personal histories and experiences, and his proposal of rapprochement to mediate ethical conflict is helpful in addressing a conflict of values between persons. His acknowledgement of the social context in informing one’s moral outlook and personal meaning structures is also instructive as well as his emphasis on an interactive relationship between patient and healthcare providers (as well as bioethicist in his case) in order to arrive at understanding and reconciliation. However, Carnevale’s account is limited. He presupposes that all parties can identify or have already identified a moral
outlook with which to inform their healthcare decision making. His focus on ethical conflict mediation and resolution is therefore restricted to external ethical conflict and does not address the internal process of parties in developing, recognizing and endorsing, or articulating their morally informed decision or opinion. But what if a relevant party (the patient, for example) is having difficulty determining her moral position or how to integrate or align her moral position with her true desire for action? Therefore, even though we are all immersed and participate in particular cultural communities it does not necessarily follow that 1) a person will identify with a particular community and develop moral outlooks consistent with that community; nor does it 2) guarantee that even if a person develops a consistent moral outlook that she will endorse or identify wholly with actions that seem to follow from such outlooks. Sometimes patients, especially those receiving life-altering information, experience a shattering of values, moral outlooks, and personal meaning structures, which may create a sense of internal conflict that prohibits them from making any healthcare decisions at all.

3.2 Account of internal conflict: Harry Frankfurt

Harry Frankfurt offers an enlightening discussion of internal conflict (1987, pp. 31-32). According to Frankfurt a person’s will for action involves an element of self reflexivity, which involves levels of desires. In establishing a will for action, a person usually has some second order desire that endorses her particular first order desire for action. For example, if a patient wishes to consent to surgery, she has a first order desire to consent and also a second order desire to want to consent. Frankfurt further distinguishes between second order desires and second order volitions. Second order
volitions are about which first order desires a person wants to govern their will for action. It matters, says Frankfurt (and I agree) whether the desires by which we are moved to act as we do motivate us because we want them to be effective in moving us, or whether they move us regardless of ourselves. Returning to my example, perhaps the patient has a competing desire not to consent to surgery. The patient’s second order volition is about which desire (“to consent to surgery” or “not to consent to surgery”) she really wants to govern her will for action. When we are generally clear about what we want and in deciding things for ourselves the process of self-reflexive endorsement is largely subconscious. It is primarily when we experience some conflict or discrepancy about what we want that we become aware of competing desires within and among levels of desires.

Within one’s reflective self-consciousness, Frankfurt says a person may experience an inner division or conflict when there is a lack of coherence within the realm of the person’s higher-order volitions themselves. In the absence of wholehearted identification with a preference there may be no unequivocal answer to the question of what the person really wants. Perhaps the person’s preferences concerning what she wants are not fully integrated because the person is ambivalent about what she wants (Frankfurt, 1987, p. 33). In the case of the patient deciding to consent to surgery or not, she might experience wanting both first order desires to be effective for action. That is, the patient might think there are reasons to make consent for surgery her will for action but also find reasons to make not consenting for surgery her will for action. In the absence of any wholehearted, unequivocal answer the patient experiences internal conflict as she is unable to identify which desire she wants to be effective in motivating
her. Besides a solely internal struggle, it might be the case that external ethical conflict initiates a sense of inner conflict if the patient were swayed by the opposing healthcare professional’s opinions; the external disagreement causing the patient’s internal sense of values, beliefs, and desires to be challenged or displaced.

Frankfurt’s analysis can be applied to Sara’s experience as she considers whether to proceed with radiotherapy. Sara is demonstrating intense inner conflict of an ethical nature. She has two second order volitions competing for her will to action. On the one hand she wants to endorse her logical side that reasons she should accept radiotherapy while on the other hand she feels compelled to listen to her intuitive side, which is urging her to make a different decision. Sara has inner conflict about which desire she wants to be effective in moving her and as she needs to account for all parts of what she is feeling, she needs some sort of integration of her desires.

*The process of identifying and endorsing*

Harry Frankfurt might say that Sara is not wholeheartedly motivated; her heart is at best divided between two possible desires for action. This division is compromising Sara’s ability for autonomy because although she is motivated by the force of her own desires Sara would also be moved to act by something other than what she really wants (Frankfurt, 1987). But what is it to wholeheartedly identify with what one really wants? Frankfurt elaborates: Someone is doing what she really wants to be doing when that person wholeheartedly identifies with that desire. Some desires are integral to a person while others are less so. What makes a desire more integral than another is not its hierarchical status (whether it is a first order desire or second order volition), but whether one decisively commits to that desire. When one decisively commits to a desire, that
decision resounds endlessly within the person– she maintains an unreserved commitment to it and no further drive to enquire into which desire to undertake remains. To decisively commit is to identify with the desire and to incorporate it into one’s sense of self, constituting something one has by one’s own will. This commitment is far from arbitrary; in the absence of wantonness (losing interest in evaluating) the person has some reason that makes the adoption of one particular commitment more relevant than another (1987, p. 36, 38).

*Limits of Frankfurt*

Frankfurt’s model of self-reflexivity involving levels of desires and his discussion of wholehearted identification illuminates what might be happening internally when a cancer patient like Sara has to make a healthcare decision but is grappling with competing desires or feeling torn between two personal meaning structures (for example, those meaning structures attributable to a pre-cancer sense of self and those meaning structures she has recently arrived at post-cancer). Because Frankfurt does not explicitly identify his account as an account of autonomy it is not immediately amendable to the project I have set out here. Furthermore, relying on his account to inform a re-conceptualization of autonomy will remain incomplete as autonomy involves more than identifying with desires but also involves a range of competencies and personal characteristics that allow one to consider, affirm or reaffirm one’s deeper concerns and values.

*Fundamental beliefs*

The idea of persons, and patients specifically, having deep concerns and values is one recognized by Frankfurt (1999) and also feminist philosophers writing on
autonomy. The strength of these writers, as seen in the case study, is that they seem to accurately attend to the actual experience of someone with cancer. Specifically, Frankfurt’s wholehearted identification or the resound, which allows for someone to decisively commit to a preference or desire, seems intuitively and practically plausible, especially when such preference fits into or is congruent with a person’s more fundamental belief system. Lacking conflict, it seems a person’s inner resolve is precisely this state of congruence.

Feminist philosopher Marilyn Friedman can help link Frankfurt’s concept wholeheartedness to autonomy. Friedman argues an autonomous person has relatively stable and enduring concerns and values that gives her over time a perspective that is specifically hers and that shows some continuity in the face of new sorts of conditions. Gaining stability in one’s values requires an internal identification and verification of these values. Typically this requires one establish an internal coherence among concerns and reflectively affirm or reaffirm these values as her own. Friedman writes, “When someone acts from such a relatively stable, enduring (though revisable over time) orientation of concerns that she tends to carry from one situation to the next and that gives her a perspective that is hers, and when her actions reflect those concerns in the two relevant senses (attentive consideration and mirroring), then (assuming no interfering conditions) a person is self-determining, or autonomous (Friedman, 2003, p. 12-13).

Friedman and Frankfurt, taken together, give what I see is an accurate and useful description of autonomy and understanding of internal conflict relevant to the cancer

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34 Note that to be wholehearted doesn’t mean that a person can’t have competing desires. All it means is that a person is committed to one or another of those desires and so no internal battle over which desire should win remains ("it eliminates the conflict within the person as to which of these desires he prefers to be his motive") (Frankfurt, 1987, p.40).
patient’s experience. Their accounts are most able to offer an understanding of the theoretical and principled basis for supporting and respecting cancer patients’ autonomy. It remains to be seen how the meaning-making intervention can support cancer patient autonomy thus understood.

3.3 Applying the meaning-making intervention

I will now return to the case study of Sara, who has to make a decision about whether to pursue radiotherapy or not and is internally divided between ‘the logical’ and ‘the intuitive’ parts of her as reasons for action. The part of Sara that she refers to as ‘the logical’ reasons that she should follow her physician’s advice and complete the treatments just to be on the safe side; however, another part of her, that she refers to as ‘the intuitive’ is pushing her away from accepting radiotherapy, having faith that she will remain cancer free. Sara is finding this dilemma particularly crippling because she is unsure just how much credibility she should attribute to her intuition. In the past, when Sara had competing desires she would always follow her intuition, believing it to be a source of light illuminating her pre-ordained path. However, her somewhat fatalistic worldview and faith in a higher power were shattered when she received her cancer diagnosis. Therefore, without this guiding fundamental framework Sara can no longer make sense of her intuitive feelings and resolve her internal discrepancy in the same way she used to. Instead she feels torn and crippled, unable to make any kind of decision because doing so, she feels, means splitting herself in two and denying the half of her that disagrees.

The meaning-making intervention
The phrases ‘making sense of’ and ‘finding or making meaning’ are used by some in the nursing research literature to describe the cognitive coping process of people with cancer and the interventions designed to support these patients in receiving and dealing with life-altering medical information. These phrases, however, are widely interpreted and the development of these theoretical concepts into practical tools and resources is by no means systematized as of yet.35

The specific meaning-making intervention that I support is one developed, tried, and analyzed by Virginia Lee et al. (2006). Describing the basis of their meaning-making intervention, Lee et al. provide a systematic literature review of “meaning-making” in the coping process of cancer patients and identify four broad categories of meaning: global meaning, appraised meaning, the search for meaning, and meaning as outcome.

On their account “global meaning” refers to existential beliefs that provide an orderly framework to (a) understand cancer against the backdrop of life experiences and future expectations, and (b) create a sense of purpose in life. So, for example, a person may fundamentally perceive the world as random and uncontrollable, which would provide the framework for understanding cancer diagnosis. “Appraised meaning” is the perception of threat or challenge associated with the experience of cancer based on the extent to which valued life goals are affected. For example, some might view their experience with cancer as a ‘challenge’ instead of a ‘loss’ depending upon how the experience of cancer fits in with their life values, beliefs, and goals. The “search for meaning” is the cognitive coping strategies aimed at reducing the discrepancy between appraised meaning and previously held global meaning. “Meaning as outcome” is the

product of the search for meaning. This may include philosophical changes, perception of personal growth, positive outcomes, and enhanced social resources (Lee et al., 2004, table 4, p. 298).

In Sara’s case, her internal conflict is primarily a result of receiving her cancer diagnosis and the shattering effect the diagnosis had on her global meaning structure, which was constituted by fundamental beliefs in a higher power, fate, and things working out for her according to a divine plan that she could glimpse through intuition.

The meaning-making intervention designed by Lee et al. (2006) identifies several exercises that healthcare professionals may use to support cancer patients in dealing with their healthcare experience. These exercises support their capacities or skills for autonomy in order to resolve the discrepancy between global and appraised meaning. Specifically, healthcare professionals work with the patient on describing her beliefs about the self in the past and present, and then formulating a conception of the self in the future. For example, healthcare professionals can ask the patient to describe her values, beliefs, and desires previous to the specific healthcare situation; the beliefs the patient has about the healthcare situation upon receiving relevant information (what the specific healthcare situation means to her) and how this is seen in relation to previous values, beliefs, and desires. Finally, the patient could be asked to formulate future goals and identify the values, beliefs, and desires that refer to these. During these exercises, healthcare professionals support the patient by empathizing with and normalizing the patient’s feelings, calling attention to exhibited patient strengths, and identifying areas where the patient can exert control in an experience that usually leaves patients feeling as if they have very little control. For example, this can take the form of reminding a patient
that she has some control over beliefs and attitudes about herself: she can be reminded that facts about the self (e.g. ‘I am worthless’) are not facts as such but attitudes that can be changed.

In the example of Sara, a healthcare professional can ask her to elaborate on her beliefs prior to her present healthcare situation. What did her belief in the trustworthiness of her intuition specifically mean and entail? What role did these feelings play in her value system prior to the present healthcare situation? Does Sara believe her somewhat fatalistic worldview was a good influence on her values, beliefs, and desires? The healthcare professional can then ask Sara to elaborate on what the present healthcare situation means to her and ask her to describe what values, beliefs, and desires she views as relevant to her particular situation. To help this process along the healthcare professional can prompt Sara to reflect upon some of her answers. Does getting sick with cancer need to compromise the relevance of Sara’s fundamental worldview like she feels it does? Are the beliefs Sara has about her intuition realistic or unrealistic – does her intuition always need to be understood as a reliable glimpse into her pre-ordained life plan? Throughout this process, the healthcare professional can use visual tools to help Sara pinpoint significant transitional periods in her life (and identify the skills Sara previously used to cope), further empathize with Sara’s difficult situation, assimilate relevant data, challenge Sara’s negative values, beliefs, and desires, and call attention to various skills and strengths that Sara has exhibited in the past in order to give her confidence in her ability to resolve her present internal conflict.
3.4 Incorporating the meaning-making intervention into routine cancer patient care

The meaning-making intervention designed by Lee et al. (2006) improves patients’ self-esteem, optimism, and self-efficacy. As illustrated in the above case study, the intervention may also help patients resolve their internal conflict. Support for mediating internal conflict is a necessary step to supporting patient autonomy as autonomy involves self-determination, which includes identifying with one’s desires so that they become “her own” and then acting on these authentic desires and knowledge. When experiencing internal conflict, a patient is not wholeheartedly identified with one or another of her desires; she feels no unequivocal answer to the question of what she wants. Her autonomy is compromised.

The principle respect for autonomy as conceived by Beauchamp and Childress (2001) is largely related to the individual, rational patient making choices and giving (or withholding) informed consent to treatment. Their concept is to this effect focused almost solely on informed consent policy and procedure.36

By focusing only or mainly on informed consent, support for autonomy in healthcare is often limited to abiding by the processes and policies designed to achieve informed consent. A typical process might involve “identifying those patients who have the capacity for choice, offering those who have this capacity the information necessary to make an informed choice, and respecting the free, informed choices they make” (Dodds 2000, p. 216). However, equating support for patient autonomy with informed

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36 Thomas L. Beauchamp and James Childress’ approach has been thought to have this effect. See especially Dodds, S., (2002). Choice and Control in Feminist Bioethics, in C. Mackenzie & N. Stoljar (Eds.), Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self, (pp. 213-235). New York: Oxford University.
consent is “narrow and undertheorized” because it assumes rational agents are equally able to reflect on choices irrespective of the social circumstances and power relations that affect choice contexts (Dodds, 2000, p. 216). It directs ethical concern towards the actions of the physician in obtaining consent and less so to the decision making process of the patient. It does very little to ensure that those choices reflect what a person truly values, wants, or believes; and, lastly, the focus on informed consent “ignores the ways in which healthcare practices influence the development and demise of the capacity for personal autonomy” (Dodds, 2000, pp.216).

A more robust concept of autonomy takes as important the social conditions and relationships that have impact on the values, beliefs, and desires and the choices one makes. Furthermore, a more robust concept of autonomy shows us that one exhibits certain skills and capacities and character attributes in order to be self-determinate. One, for example, must feel worthy of considering her various options and exercising skills to navigate these options. She must also have trust in her abilities to make good decisions in light of this information. Aside from these conditions, being self-determinate also requires that a person wholeheartedly identify with certain desires, in this sense, authenticating them as “one’s own” in order to form a relatively stable, enduring orientation or perspective. Once autonomy is seen in this light, the principle of respecting autonomy involves supporting autonomy as being self-determinate is a process that one works at over time and that one arrives at in various degrees.37

Supporting patients with the meaning-making intervention in resolving their internal conflict, a particular kind of psychological distress, is a necessary step to

supporting and respecting their autonomy in healthcare decision-making. Meaning-making interventions, under the feminist principle of respect for autonomy, should be included in standard cancer patient care. This is the case because of the nature of receiving a life-altering diagnosis. Although not all cancer patients will experience internal conflict or psychological distress – it should at least be offered as part of routine care. Psychological distress may creep up unexpectedly for a patient; for example, if something goes wrong with her care (some treatment does not work or she is wait-listed for a time-sensitive treatment) the patient may experience sudden psychological distress. This highlights the need for ongoing provision of the meaning-making intervention.

Conclusion

Integrating meaning-making interventions into standard cancer patient care faces a number of barriers. The importance of addressing practical barriers such as increasing physician or healthcare professionals’ knowledge about the intervention as well as improving cost-effectiveness and feasibility studies as well as theoretical concerns about the model of medicine and the physician-patient relationship becomes clear when we are moved to support patient autonomy.

There are still legitimate considerations to address besides the above mentioned barriers, particularly the question of which healthcare professionals should be responsible for providing the intervention. Oncology nurses with some training or knowledge of psychosocial care would be ideal as they have the most consistent contact with patients and opportunity to develop relationships built on trust. This would allow the intervention to reach all oncology patients instead of a select group that might receive support or counseling through cancer patient support centres or programs. Although these centres or
support programs are a fantastic resource, the trick is to make resources available to all cancer patients and not just those who pro-actively seek them out.\textsuperscript{38}

Working the intervention into patient-centered care approaches for oncology might prove helpful in order to make the meaning-making intervention a ubiquitous care tool. Recent studies in healthcare disciplines outside of oncology make the link between support for autonomy and psychosocial outcomes.\textsuperscript{39} In a study comparing the effects of autonomy support on glycemic control and patient satisfaction for people with diabetes, researchers found clinician autonomy support to be reliably measured and moderately correlated with psychosocial and biologic outcomes related to diabetes self-management (Williams et al., 2004). Under this study autonomy support is part of patient-centered care and involves a dynamic relationship between practitioner and patient where the practitioner “elicits and acknowledges patient perspective, supports patient initiatives, and avoids being controlling or judgmental of the patient” (Williams et al., 2004, p.40). The ultimate goal of this support is to bring patients to a place where they can then make a clear and informed choice about treatment (including accepting no treatment), and in supporting them in reaching their health goals (Williams et al., 2004).

Although the support tool is different than Virginia Lee et al.’s meaning-making intervention, Williams et al.’s belief that healthcare practitioners can be trained to be autonomy supportive and their argument for quality improvement efforts’ need to pay greater attention to the psychosocial (patient competence, satisfaction, depression) in addition to the physiologic (glycemic control) is shared.

\textsuperscript{38} These centres, such as Gilda’s Club, wouldn’t take the place of the meaning-making intervention as the intervention offers more individualized support than group counseling sessions and is targeted specifically to helping the patient cope with her life-altering experience.

\textsuperscript{39} Note that Lee et al.’s research does not make the link to patient autonomy but only proves supportive to patient capacities (such as self-esteem) that others argue are necessary for autonomy.
Psychosocial oncology care advocates have many barriers to address in their quest to incorporate psychosocial support into standard cancer patient care. In times of advocating practical changes it might be easy to overlook bioethical barriers. However, the bioethical principle respect for autonomy, when reconsidered from a feminist standpoint, can motivate healthcare professionals and organizations to make changes to address the other psychosocial barriers in healthcare delivery and priority setting.

In this thesis I have argued that the positive effects meaning-making interventions have on cancer patient well-being, self-esteem, ability to cope, optimism, feelings of self-efficacy are not to be taken lightly. Although policy exists that supports including psychosocial care in cancer patient care these policies have not been incorporated into routine practice. This is a travesty as many will not have the opportunity to experience the very positive benefits the meaning-making interventions elicit. But, so long as we are concerned with providing quality healthcare and are committed to respecting patient autonomy, when autonomy is reconsidered from a feminist perspective that acknowledges support for capacities and skills and recognizes the self as socially situated, we are committed to providing a meaning-making intervention in routine cancer patient care. The meaning-making intervention, as described in my case study, is particularly equipped to help cancer patients resolve their experience of internal conflict and, as such, indirectly support cancer patients’ autonomous capacities. With other disciplines such as diabetes research acknowledging the benefits of autonomy support as part of patient-centred care, I find little reason why the same patient-centred model couldn’t support including a meaning-making intervention in routine oncology care.
References


